



Long Term Care Coordinating Council
Alzheimer's State Plan Work Group
Family Caregivers Task Force
February 6, 2014
Rhode Island Quality Institute
50 Holden St. Suite 300
Providence, RI 02908

DRAFT MINUTES

Donna Leong Marge Angilly Leslie Jackson
Amanda Clarke Laurie Johnson

1) Welcome and introductions

Donna Leong called the meeting to order at 9:00 a.m. Many people are drawn to the Alzheimer's State Plan meetings because of their strong personal connection to Alzheimer's disease and related dementias.

2) Review of last meeting

Donna began the meeting with a review of the previous meetings, which discussed the Alzheimer's State Plan and the current resources in the community available to family caregivers.

3) Primary care providers and Alzheimer's diagnosis protocol

The meeting began with a discussion of the role of primary care providers in giving patients and their families the necessary information and treatment upon initial diagnosis. There have been findings that the treatment being received is not up to an ideal standard. The discussion was surrounded on potential ways of improvement. Suggestions included an exploration of the unstandardized diagnostic tests being used and meetings with physicians and the RI Medical Association in order to learn about the protocols used.

Laurie Johnson expressed concern with the current processes of diagnoses, which remain

unstandardized and could potentially lead to an incorrect diagnosis. Tests being used include the *MoCA Scores*, *BIMS*, *Mini Mental Status Exams*, *FASTs*, *Cat Scans*, *MRIs*, etc. There have been misdiagnoses of Alzheimer's, causing unnecessary treatment and emotional harm to individuals and their family members. There is an increasing need for standardization of testing, a higher consideration of alternate diagnoses, and further exploration of how and why individuals develop the disease.

4) Alzheimer's Association training manual

The next topic of discussion is the usage of the existing training manual developed by the Alzheimer's Association. Other resources available for caregivers include 4-week family programs, caregiver wellness programs, 15 support groups, etc. In order to increase participation, the Alzheimer's Association posts ads in local papers and there is an upcoming Conference in March 2014. It was determined that there is a need to amplify the reach of information being brought to those affected by Alzheimer's. In order to implement resources, there were suggestions for contacting churches, living residences, *Kathleen Kelly*, the use of national chat rooms and awareness events.

There are some predicted stumbling blocks in these initiatives. The first is potentially physicians lacking willingness to be further trained. Additionally, there is a lack of motivation for family caregivers to participate in the programs directed at them rather than the patient, for many do not consider themselves caregivers. Also, many resources available are not available in alternate languages. Finally, there are very few practices with available case managers trained and allocated to deal with those being diagnosed with and living with Alzheimer's or Dementia.

5) Next Meeting

A suggested topic for the next meeting was the use of peer mentorship programs. Rhode Island currently does not have a network of any similar programs in the state.